Fall 1999

AsthmaMEMO

NAEPP Kicks Off Partnership With Asthma Coalitions

In an exciting move to support grassroots asthma control efforts, the National Heart, Lung, and Blood Institute (NHLBI) convened a meeting in November called "Strengthening Asthma Coalitions: Thinking Globally, Acting Locally."

The meeting brought together representatives from the NHLBI's National Asthma Education and Prevention Program (NAEPP) and 40 asthma coalitions from around the country. Its goals were to increase recognition of World Asthma Day, promote networking among asthma coalitions, identify effective local interventions, and find opportunities for the NAEPP to support the coalitions.

The opening session outlined the day's full agenda and described the distinctive role of coalitions. Dr. Noreen Clark, professor and dean, University of Michigan School of Public Health, stressed that coalitions bring a considerable amount of knowledge and experience to the table and hold great promise for asthma control. In addressing childhood asthma, one of the participants' top priorities, she said, "The child with asthma is in the middle of concentric circles—family, school, health care providers, community organizations, and policymakers. The charge of coalitions is to organize the circles to work together and educate each other to help control asthma."

In addition to plenary sessions, the workshop featured lively breakout groups that allowed attendees to compare notes on their challenges and successes. These smaller, more focused sessions explored creative ways to control asthma, including using the media and technology to deliver messages, optimizing patient education, and conducting outreach in inner city communities. Coalition members learned about promising NAEPP initiatives and discussed strategies to help achieve their common objective of controlling asthma in our Nation's communities.

Education is the key to the fulfillment of that objective, said former NAEPP Coordinator Robinson Fulwood: "Communities continue to struggle with the problem of asthma, and there is much work to be done. Education is essential—for professionals, patients, and the public." One of the NAEPP's primary charges is educating health care providers to diagnose and manage asthma more effectively by using the NAEPP clinical practice guidelines, as presented in the *Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma*. Finding effective ways to encourage the implementation of the guidelines was a topic of discussion throughout the day.

(continued on page 8)

NATIONAL INSTITUTES OF HEALTH
NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

Contents

Letter From the Director

World Asthma Day, Looking Forward

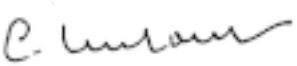
December 11, 1998, marked the first observance of World Asthma Day, a call for global action to substantially reduce childhood deaths and disability from asthma. The event set specific goals for the next 5 years: to reduce childhood asthma deaths by 50 percent, reduce the number of school days lost due to asthma by 50 percent, and cut the number of childhood hospitalizations due to asthma by 25 percent. The theme of the day was "Help Our Children Breathe."

The organizers of World Asthma Day, in conjunction with the NAEPP and a national network of asthma coalitions, distributed information to help promote the event and increase public awareness of asthma. World Asthma Day was coordinated by the Global Initiative for Asthma, which was established by the World Health Organization and the NHLBI, and the European Respiratory Society. Supporting organizations in the United States included the NHLBI; the American Academy of Allergy, Asthma, and Immunology; the American College of Chest Physicians; and the American Thoracic Society.

In recognition of World Asthma Day, the NHLBI launched a new Web site, the Asthma Management Model System (AMMS). The AMMS is an exciting interactive tool to help health care professionals, researchers, and public health planners at home and abroad perform a variety of high-tech applications. Designed by the NAEPP, this Web-based system provides users with the ability to quickly formulate research questions and access key databases, to retrieve the latest treatment guidelines and published literature, and to obtain continuing medical education credits. Another feature of the AMMS is the Asthma Coalition Exchange, a site that allows users to participate in online forums and discussions to foster information sharing and networking among community-based asthma coalitions throughout the country. The AMMS is described in more detail later in this issue of *AsthmaMemo*.

Development of the Asthma Coalition Exchange resulted from an extraordinary gathering of community asthma coalitions and the NAEPP. This workshop brought together more than 40 asthma coalitions from around the country. Its goals included promoting networking among asthma coalitions, identifying effective local interventions, and finding opportunities for the NAEPP to further support coalition efforts.

Dozens of asthma coalitions are reaching out to their communities—through schools, medical and public health settings, and worksites—to help control asthma. These partnerships have an enormous potential to improve the quality of life for patients with asthma. Because coalitions are part of the fabric of their communities, they can be a vital resource for their neighbors who must live, learn, and work with asthma every day. It is only by joining forces in this way within our communities, our Nation, and our world that we can amass the will, the knowledge, and the resources we need to control asthma. ■



Claude Lenfant, M.D.
Director, NHLBI

In the Spotlight

A Decade of Progress, A Commitment to the Future

The NAEPP Coordinating Committee met in Bethesda, Maryland, on March 21 to celebrate the program's 10th anniversary. The NAEPP began in 1989 with 21 member organizations; today it includes 38 organizations and can boast an impressive list of achievements.

The celebration's welcoming remarks were made by Dr. Gary Rachelefsky, the American Academy of Pediatrics representative to the NAEPP Coordinating Committee, and by Dr. Claude Lenfant, NHLBI director and Coordinating Committee chairman. Dr. Donald Lindberg, director of the National Library of Medicine (NLM), invited the attendees to visit the new "Breath of Life" exhibit at the NLM on the National Institutes of Health campus (see article on page 5).

Recounting some of the NAEPP's history and milestones were NAEPP Coordinating Committee members Dr. Albert Sheffer of the American Academy of Allergy, Asthma, and Immunology; Dr. Robert Barbee of the American College of Chest Physicians; and Dr. Noreen Clark of the American Lung Association (ALA). Some of the milestones they mentioned are listed in the sidebar. Keynote speaker Dr. William Busse of the University of Wisconsin presented a brief history of the scientific understanding of asthma and predicted that the future would elucidate the roles played by genetics, allergies, immune responses, and environmental factors.

(continued on page 4)

NAEPP Milestones

March 1989:	First meeting of the National Asthma Education Program (NAEP) Coordinating Committee with 21 organizations attending.
August 1989:	Expert Panel on the Management of Asthma convened.
February 1991:	*Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma (EPR)* released.
September 1991:	Publication of *Your Asthma Can Be Controlled: Expect Nothing Less* and *Managing Asthma: A Guide for Schools*.
October 1992:	Release of the *Asthma Management Kit for Clinicians*, a package of asthma materials to facilitate partnerships between clinicians and patients.
November 1993:	Name changed to National Asthma Education and Prevention Program (NAEPP) to emphasize focus on prevention.
Fall 1994:	*Making a Difference—Asthma Management in School* video distributed, along with written materials, to school personnel.
June 1995:	Second Expert Panel commissioned.
February 1996:	*Considerations for Diagnosing and Managing Asthma in the Elderly* published.
February 1997:	*Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma (EPR-2)* released.
November 1998:	*Strengthening Asthma Coalitions: Thinking Globally, Working Locally* launched to stimulate implementation of the EPR-2 guidelines locally.
March 1999:	10th Anniversary celebration.

(continued from page 3)

Words of Appreciation

The celebration was an opportunity to recognize the contributions of many individuals to the NAEPP.
Dr. Lenfant formally thanked the many NAEPP Coordinating Committee members, chairs, and vice chairs; members of the School Subcommittee; members of the NAEPP Expert Panel; and other invited guests for their contributions.

In addition, Dr. Barbee presented a plaque to Mr. Robinson Fulwood, former NAEPP coordinator, in appreciation of his "outstanding leadership."

Dr. Lenfant (left) presents award to Dr. Albert Sheffer, who chaired the first Expert Panel.

Dr. William Busse (left), the event's keynote speaker, discusses a point with former NAEPP Coordinator Robinson Fulwood.

From the NAEPP Coordinator

Welcome Asthma Coalitions!

Since its inception a decade ago, the ultimate goals of the NAEPP have been to enhance the quality of life of asthma patients and to decrease asthma-related morbidity and mortality. A key strategy in achieving these goals is to develop partnerships. At the national level, the NAEPP brings together organizations and experts to develop consensus documents, clinical practice guidelines, and professional education materials to improve the diagnosis and management of persons with asthma. In the past 10 years, the NAEPP has also developed consumer education materials for use in a variety of settings—for instance, medical care sites, schools, and local pharmacies—to help patients better manage their asthma and to inform the public about the seriousness of the disease.

At the recommendation of our national Coordinating Committee, during the past year we expanded our efforts to work with intermediaries at the local level, namely, local asthma coalitions. We are proud to recognize their unique perspective and expertise in implementing creative solutions to problems. The NAEPP understands that interventions must be tailored to reflect the needs of individual communities and that the sustaining power of interventions comes from the support, energy, and resource mobilization that occur at the local levels.

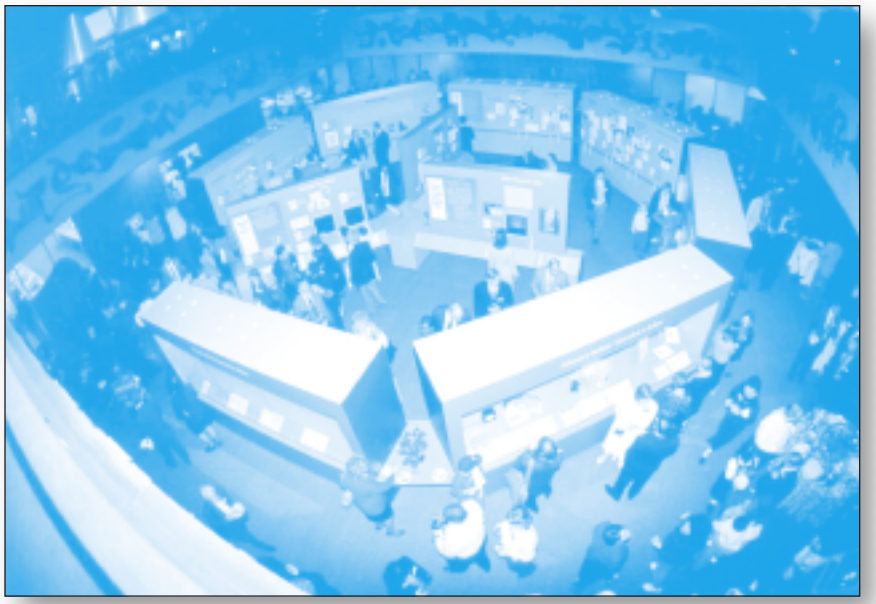
At the November workshop described in this issue of *AsthmaMemo*, the representatives from these grassroots efforts greatly added to our understanding of the challenges faced by coalitions at the local level and the enormous energy and creativity already at work addressing those challenges. Participants also provided us with a number of ideas for how the NAEPP might facilitate collaborative activities at the local public health level.

In response to their feedback, we have already launched a new Web site, the NAEPP Asthma Coalition Exchange. We hope you will visit it through http://www.nhlbi.nih.gov. Within the next several months, we look forward to announcing additional new initiatives to fight asthma at the local level. Check our Web site for details.

By working together with both our local and our national partners, we can effectively harness and focus our collective energies to implement positive and lasting change in the way asthma is managed in this country. We look forward to working with each of you in those efforts. ■

Diana K. Schmidt

Diana Schmidt, M.P.H.



Aerial view of the entire "Breath of Life" exhibit.

"For the past 10 years, the NAEPP has spearheaded efforts—both national and community-based—to move asthma onto the public agenda. This exhibit expands upon these efforts by putting a face on this condition and bringing it to people throughout the country."—Claude Lenfant, M.D., NHLBI director and NAEPP chairman

"Breath of Life" Exhibit Debuts

A unique interactive exhibit on asthma opened on March 22 at the National Library of Medicine (NLM) on the campus of the National Institutes of Health in Bethesda, Maryland. It will remain at the NLM until June 2000 and will then travel to 10 cities throughout the United States. The exhibit features the experiences of people with asthma and efforts to understand and control the disease.

The opening of the exhibit featured special guests Jackie Joyner-Kersee and Nancy Hogshead, both Olympic gold medalists who have asthma. Sesame Street characters performed as part of the "A Is for Asthma" Childhood Asthma Awareness Project.

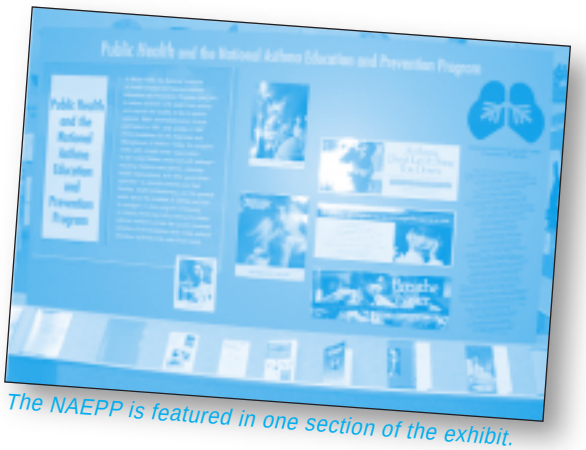
The exhibit's debut coincided with the NAEPP's 10th anniversary. It was developed by the NLM in collaboration with the NHLBI, the National Institute of Allergy and Infectious Diseases, and the National Institute of Environmental Health Sciences.

The "Breath of Life" exhibit provides a comprehensive look at asthma, including how it was viewed in ancient times, its recognition as a separate disease in the 19th century, and the transformation of asthma treatment. It also focuses on current efforts by physicians and patients to manage asthma, and current research and public health efforts, including the work of the NAEPP.

The following are some highlights of the "Breath of Life" exhibit:

- "Faces of Asthma," an interactive video featuring Americans who share their thoughts on the impact asthma has had on their lives.
- "The Immune Response in Asthma," a narrated animation that describes the cellular basis for asthma symptoms.
- "Winning With Asthma," an interactive soccer game for young people that gives facts on exercise-induced asthma.
- A video in which Sesame Street Muppets sing, dance, and talk about the needs of Dani, a new Muppet character with asthma.
- A wall of photos of famous asthma sufferers, such as Peter the Great, Charles Dickens, John F. Kennedy, and Bob Hope.
- Earphones through which visitors can hear musical selections by asthma sufferers including Beethoven, Vivaldi, Leonard Bernstein, and Liza Minnelli.
- A bank of computers with online resources on asthma.

"This exhibition will help inform people of all ages that asthma is common and treatable and that research is leading to important new insights into asthma and its prevention and treatment," said Anthony S. Fauci, M.D., director, National Institute of Allergy and Infectious Diseases. ■



The NAEPP is featured in one section of the exhibit.

AsthmaNet

NAEPP Launches Asthma Management Model System (AMMS)

Physicians who want to provide the most up-to-date diagnostic and treatment methods for their asthma patients can now find, on one Web site, virtually all the scientific literature on chronic asthma that has ever been published. The NHLBI launched the new site on December 11, World Asthma Day.

The site, called the AMMS, was developed by an international panel of experts first convened in 1997 by the NAEPP with the goal of helping improve the diagnosis and treatment of asthma. AMMS can be accessed through the NHLBI homepage at http://www.nhlbi.nih.gov.

AMMS brings together several high-tech functions within one integrated system for clinicians, researchers, public health planners, and others concerned about asthma. The system has three main components:

- **Research mode** links to and integrates a variety of searchable databases and other resources.
- **Education mode** provides immediate access to clinical practice guidelines, materials for professional and patient education, and continuing education opportunities.
- **Communication mode** allows the user to e-mail the Webmaster, register for updates by e-mail, and connect with online discussion groups.

In the research mode, the interactive AMMS lets users quickly formulate research questions and access key databases. After the user selects search terms, the system formulates a question that asks what effect a selected treatment will have on a selected outcome in asthma patients for whom selected conditions or factors are known. It then retrieves relevant information from major scientific databases such as MEDLINE, CRISP, and CORDIS and documents from Federal Government agencies like the Centers for Disease Control and Prevention and the Food and Drug Administration.

Said NHLBI Director Dr. Claude Lenfant, "The AMMS provides an important tool to help health care professionals, researchers, and public health planners at home and abroad reduce the burden of asthma."

The Asthma Coalition Exchange

Within the AMMS, users can access

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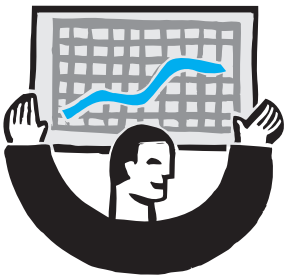


AsthmaFacts

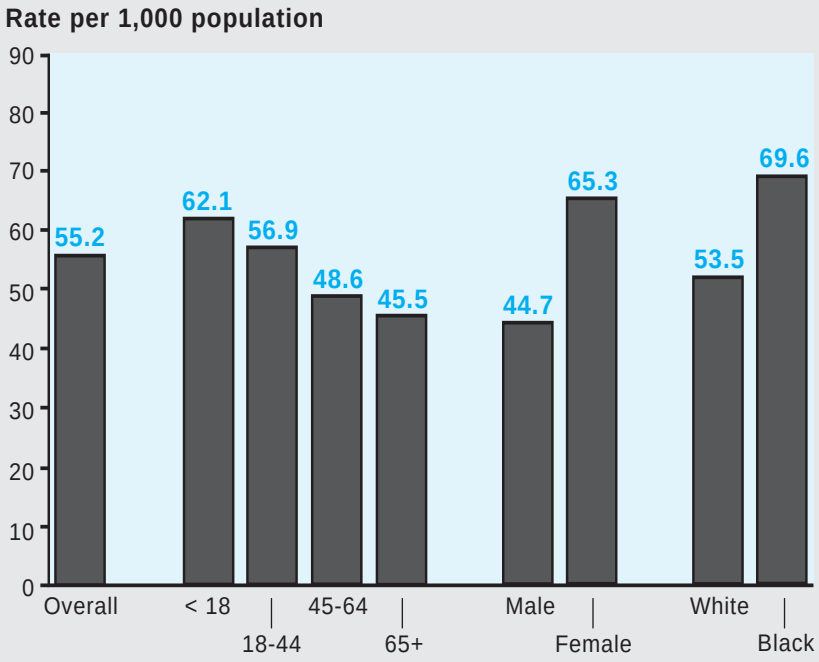
Data on Asthma

In the United States in 1995, asthma affected an estimated 14.9 million persons, causing more than 1.5 million emergency department visits, about 500,000 hospitalizations, and more than 5,500 deaths. Asthma disproportionately affects children and blacks. The burden of asthma has been increasing over the past 20 years, especially among children.

- **Prevalence.** The prevalence of asthma has been increasing since the early 1980s for all age, sex, and racial groups, but especially among children. The overall age-adjusted prevalence rose 75 percent from 1980 to 1993–94. During this same period, the prevalence among children younger than age 4 increased 160 percent, from 22.2 per 1,000 to 57.8 per 1,000.
- **Emergency Department Visits.** Between 1992 and 1995, the age-adjusted rate of emergency department visits for asthma increased from 58.8 per 10,000 to 70.7 per 10,000. This rate increased more among females (61.4 to 82.3 per 10,000) than among males (55.5 to 57.8 per 10,000).
- **Hospitalizations.** In 1995, the overall hospitalization rate for asthma was 19.5 discharges per 10,000 population, with an average length of stay of 3.7 days. The rate among blacks was 3.5 times that among whites (42.7 versus 11.8 per 10,000, respectively).
- **Mortality.** The rate of age-adjusted mortality for asthma increased steadily over the past 20 years—from 0.93 per 100,000 in 1979–80 to 1.49 per 100,000 in 1993–95. This rate has been higher and has increased faster among blacks than among whites.
- **Costs.** In 1998, the direct and indirect costs of the disease totaled $11.3 billion. Hospitalization accounted for the single largest cost ($3.6 billion).

These data can be found in the *Data Fact Sheet: Asthma Statistics* (see page 10).

Prevalence of Asthma, 1996



In 1996, the prevalence of self-reported asthma was 55.2 per 1,000 persons. The prevalence was higher among children than adults and higher among blacks than whites.

("Asthma Coalition" continued from page 6)

the Asthma Coalition Exchange site. This site is designed to foster information sharing and networking among community-based asthma coalitions throughout the United States. The Asthma Coalition Exchange is part of the NAEPP's larger effort to develop partnerships with local asthma coalitions to help implement change in the way asthma is managed at the community level. Through the site, coalitions can learn about each other, communicate through discussion forums, and join a coalition listserv.

Add this Web address for the Asthma Coalition Exchange to your list of favorites: www.nhlbisupport.com/asthma/coalitioncorner/coalition.htm.

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Community Asthma Coalitions Defined

A community asthma coalition is a broad-based, multi-organizational, community partnership that brings together the public, private, or non-profit sectors in a sustained effort to reduce asthma morbidity and mortality and improve quality of life for asthma patients and their families.

Examples of key stakeholders and members include public health departments, voluntary organizations, community-based organizations, professional associations, patients and their families, community and private hospitals and clinics, managed care organizations, health care providers, social services, public and private schools, religious organizations, recreational organizations, local businesses, local media, and elected officials.

The NAEPP welcomes joint efforts with coalitions that share its goals and meet the needs of their communities.

Why Join Forces?

As part of its strategy, the NAEPP works with public and community health organizations to reach key audiences who can impact the way asthma is managed at the local public health level. Local asthma coalitions that strive to improve asthma morbidity and mortality in their communities are ideal partners for these efforts.

Most of the coalitions that the NAEPP has identified are young and staffed by volunteers (see box), but they have enormous energy and talent and represent a strong force for change. Said Dr. Claude Lenfant, director of the NHLBI, "We believe that these coalitions can be powerful and effective mechanisms for implementing change at the community level while maintaining a unique sensitivity to local needs."

The workshop was an important first step toward gaining a better understanding of community asthma coalitions, which will help the NAEPP to facilitate collaborative activities at the local public health level. See pages 11–18 for a summary of the highlights of the meeting and breakout sessions.

Profile of Community Asthma Coalitions

In the summer of 1998, the NAEPP conducted an assessment of community asthma coalitions across the country. Following are the goals, target populations, and accomplishments most frequently mentioned by the coalitions.

Goals

- Reducing morbidity and mortality and improving quality of life
- Providing patient, professional, and public education
- Providing education in schools and child care settings
- Promoting the NAEPP guidelines
- Conducting research and evaluation

Target Populations

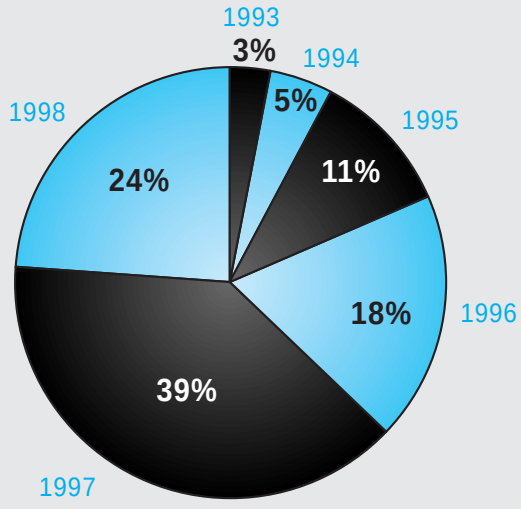
- Health care providers
- Child care industry and school personnel
- Children
- Parents
- Minorities
- High-risk groups
- Inner-city populations
- Low-income people

Accomplishments

- Conducting needs assessments
- Developing educational materials for patients and the public
- Implementing school staff training programs
- Initiating screening efforts

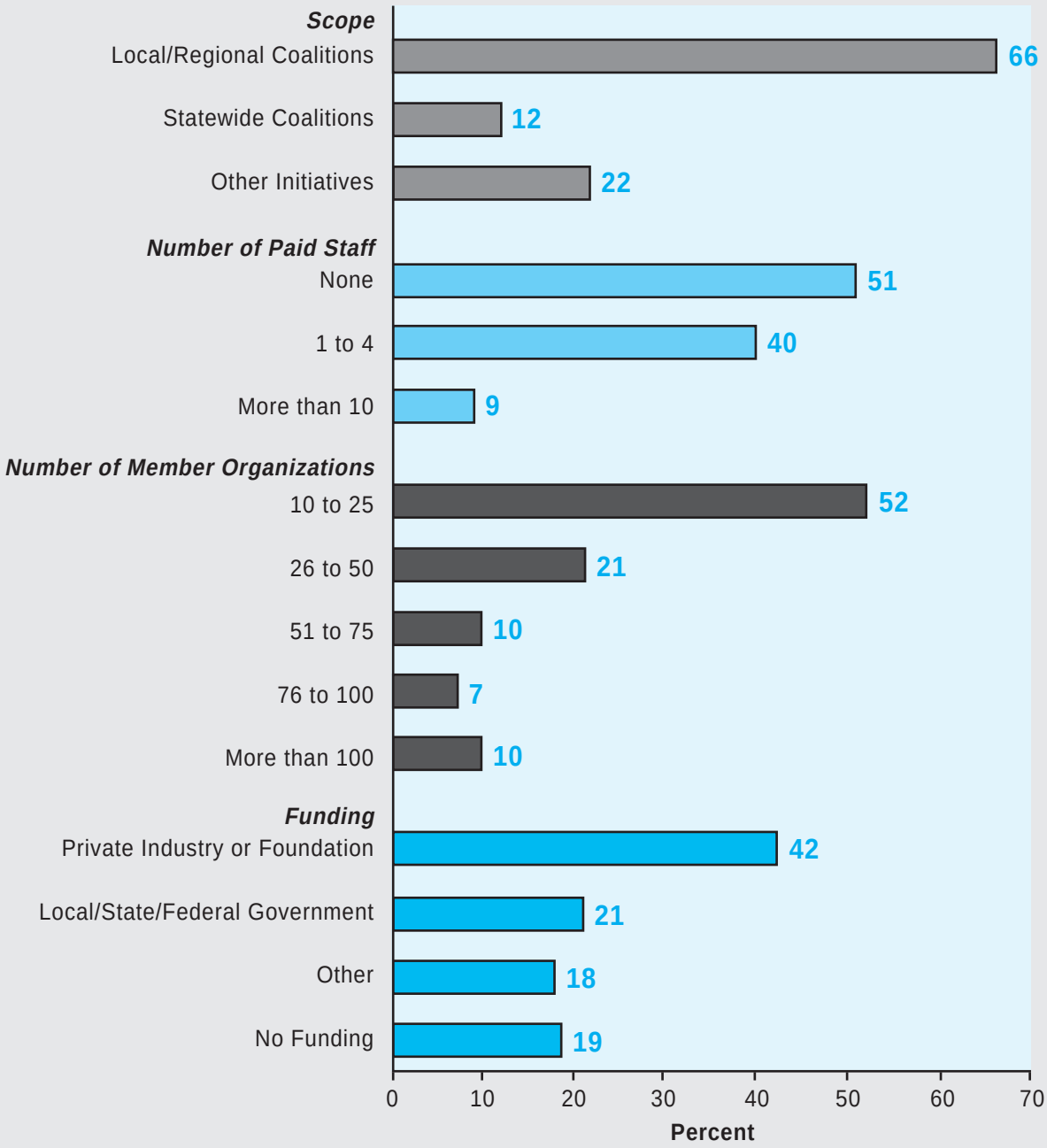
See page 9 for more findings from the assessment. ■

Growth of Asthma Coalitions Since 1993



By October 1998, 44 coalitions had been identified. Most of them had been organized for less than 2 years.

Data on Asthma Coalitions from the NAEPP Assessment



New at the NHLBI Information Center

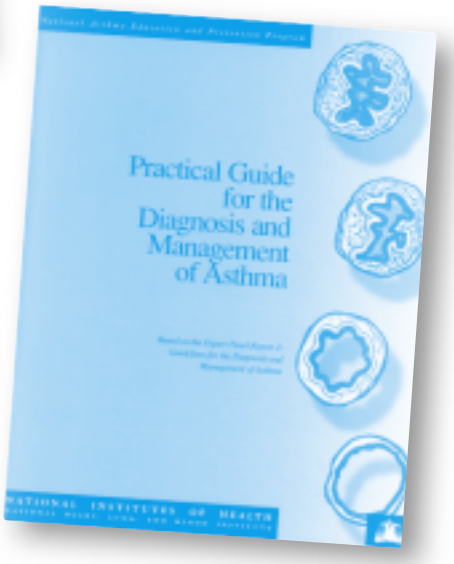
Data Fact Sheet: Asthma Statistics (#55-798, $1 each/25 copies, $12.50/100 copies, $40). The latest statistics on asthma—including prevalence, emergency department visits, hospitalizations, mortality, and costs of asthma—can be found in *Asthma Statistics*, a revised issue of the *NHLBI Data Fact Sheet*. The four-page fact sheet includes details on how the statistics have changed since the early 1980s and six graphs that illustrate trends. See the article on page 7 for some of the data highlighted in this publication.

Practical Guide for the Diagnosis and Management of Asthma (#4053 $5 each/25 copies, $106.25/100 copies, $400). Busy primary care providers can turn to the *Practical Guide for the Diagnosis and Management of Asthma* for concise information about the NAEPP's clinical practice guidelines. The 60-page manual extracts practical information from the *Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma*.

The *Practical Guide* includes sections on initial assessment and diagnosis of asthma, pharmacologic therapy for long-term management, control of factors contributing to asthma severity, and periodic assessment and monitoring.

Two laminated cards are inserted in the manual for quick reference by health care providers. One card lists clinical features used to classify severity, medications, and daily dosages for inhaled steroids for children younger than age 4; the other card has similar information for older children and adults. The *Practical Guide* also includes a variety of implementation aids, such as glossaries of medication brand names, patient self-assessment forms, and reproducible patient handouts.

The *Practical Guide* can be ordered from the NHLBI Information Center and is also available on the NHLBI Web site at http://www.nhlbi.nih.gov/nhlbi/lung/asthma/prof/practgde.htm.



Direct Mail Campaigns Target Managed Care Organizations and Medical Schools

Last fall, the NAEPP mailed packets of asthma materials to approximately 600 managed care organizations (MCOs). The purpose of the mailing was to encourage MCOs to integrate asthma materials and information into their health care systems. The packets were sent to the attention of medical directors, patient education directors, and newsletter editors. The mailings included the *Practical Guide*, patient education materials, and publications for nurses and pharmacists. Order forms included in the mailings were coded to permit assessment of how successful the mailings were. More recently, another mailing was sent to medical school faculty and residency program directors. This mailing included the *Practical Guide* and a flyer on the Asthma Management Model System.

Highlights From "Strengthening Asthma Coalitions: Thinking Globally, Acting Locally"

Asthma Surveillance: An Overview From Chicago

Dr. Kevin Weiss, director of the Center for Health Services Research at Rush Primary Care Institute in Chicago, presented findings from the Chicago Asthma Surveillance Initiative (CASI), a major ongoing survey of asthma care and outcomes in the Chicago area. CASI has surveyed Chicago-area hospitals, emergency departments (EDs), primary care physicians (PCPs), asthma specialty physicians, managed care organizations, and pharmacies. In 1996, more than 60 of the 89 hospitals in the area responded, including small and large, urban and suburban, and teaching and nonteaching hospitals. A random sample of 405 primary care physicians also was surveyed, and 60 percent responded. Some of the survey findings follow.

Survey Results

- There are 19,000 asthma hospitalizations in the Chicago area annually.
- Few hospitals have community-based asthma programs.
- Almost all hospitals routinely provide peak flow monitoring; most provide instruction in peak flow monitoring and inhaler technique.
- There are more than 70,000 asthma ED visits in the Chicago area annually.
- Most EDs provide little formal asthma education to patients.
- Two-thirds of all asthma care in the Chicago area is provided by PCPs.

The survey results show that although many clinicians are providing excellent asthma care, there are considerable variations. Although the survey examined asthma care practices in Chicago, Dr. Weiss believes that the results probably reflect practices in many areas.

Whereas national asthma statistics are readily available, local data such as the CASI survey results are scarce. Dr. Weiss emphasized the need to collect, analyze, and use local data to spur local action and bolster advocacy efforts. He urged coalitions to gather evidence of the effect of asthma on communities, such as figures on school absenteeism and lost work days.

Data on Asthma Care in Chicago

Hospital Inpatient Care	Percent
Have asthma management guidelines	40
Developing guidelines	20
Have critical pathways	35
Developing pathways	15
Routinely provide asthma education to inpatients/outpatients	55/33
Prescribe inhaled anti-inflammatory medications to discharged inpatients	75
Emergency Department Care	
Hospital admissions as a percent of asthma ED visits	5–40
ED patients who relapse within 7 days	5–25
Use written protocols or guidelines for assessment and treatment	50
ED asthma patients who:	
Take inhaled corticosteroids at home	25
Are given oral corticosteroids during their visit	41
Are given prescriptions for oral corticosteroids	50
Are prescribed inhaled cromolyn or corticosteroids	20
Are given antibiotics upon discharge	20
Primary Care Physicians	
Aware of NAEPP guidelines	87
Recommend home peak flow monitoring for nearly all patients with moderate or severe asthma	48
Provide written treatment plans for nearly all asthma patients	30
Prescribe an inhaled corticosteroid for nearly all patients with moderate persistent symptoms	60
Provide asthma education or referrals for education	57
Deliver education informally by a doctor or nurse	71
See patients only when symptomatic	19

Effective Use of Data—Determining Needs and Measuring Outcomes

This breakout group, facilitated by Dr. Weiss, director of the Center for Health Services at Rush Primary Care Institute, recommended the following data collection efforts.

Sources of Local Data

- School surveys (entrance, prevalence, health records surveys).
- Sports participation surveys.
- Quality-of-life surveys, including surveys of members of health maintenance organizations.
- Surveys of physicians and hospitals to assess adherence to NAEPP guidelines (e.g., coding of asthma severity, prescription practices, and patient education practices).
- The International Study of Asthma and Allergies in Childhood (ISAAC), a large-scale, international survey of childhood asthma that provides a good model for data standardization and a methodology for community sampling.
- Hospitalization discharge data (length of stay and ED visits).
- Accurate asthma mortality data.

Data That Can Influence Policy Change

- Prevalence data.
- Cost-related data, both direct (hospitalizations and ED visits) and indirect (missed school and work days).
- Prescription and medication usage.
- Number of cases of undiagnosed and uncontrolled asthma.
- Number of schools without asthma management plans.

Stakeholders in Data Collection Efforts

- Physicians.
- City and county boards of health.
- Chambers of commerce, local businesses.
- Boards of education.
- Academic medical centers.
- Government officials.

Members agreed that data standardization and a common definition of asthma are needed to allow comparisons of data across communities. The NAEPP may be able to support these goals on a national level.

Community-Based Asthma Control: Setting Local Agendas

The needs of the communities that asthma coalitions serve can seem overwhelming, particularly in our Nation's cities. Urban public health expert Dr. Nicholas Freudenberg, director of the Program in Urban Public Health at Hunter College of the City University of New York, suggested that grassroots asthma organizations begin with the following priorities:

- Improving access to primary care for children and adults with asthma.
- Giving health care providers the knowledge and skills to manage asthma optimally.
- Making cultural and linguistically appropriate information on asthma widely available.
- Increasing self-management skills of persons with asthma and their families.
- Assisting schools to develop educational and health-related services for children with asthma and their families.
- Identifying local sources of pollution that may trigger wheezing and reducing exposure to these substances.
- Increasing the capacity of families to improve their home environment and reduce exposure to allergens and irritants.
- Monitoring asthma prevalence and incidence to improve intervention activities.

Dr. Freudenberg acknowledged that the agenda is an ambitious one and cautioned against tackling too much. Coalitions should have a well-defined mission—one that is neither too broad nor too narrow—and the coalition's members should know what that mission is.

"The coalition's job is to develop a process that acknowledges different perspectives, builds trust, and allows for constructive criticism," he said.

Societal Changes Needed

Asthma is a national problem, Dr. Fruedenberg observed, so it demands societal change in addition to community activism. He proposed the following goals for a national agenda to control urban asthma, acknowledging that such an agenda would require policy changes:

- Reducing the number of children and adults without health care insurance.
- Improving quality of primary care and access to care for urban populations.
- Increasing supply and improving quality of housing for low-income populations.
- Developing Federal, State, and local funding streams that can support and sustain asthma control activities over extended periods.
- Integrating asthma control activities into existing systems such as schools, child care programs, youth programs, workplaces, primary health programs, correctional facilities, and job training programs.
- Establishing coordinated and systematic local, State, and national systems for asthma surveillance.
- Developing and supporting a research agenda on urban asthma that studies policy and organizational barriers to control.

Outreach in Inner-City and Other High-Risk Communities

This breakout group, facilitated by Dr. Norman Robbins, Case Western Reserve University, discussed ways to facilitate effective asthma control in inner cities, where residents are disproportionately affected by asthma. To be successful, local coalitions must address complex variables such as poor access to quality health care and housing, diverse cultural and linguistic needs, and environmental allergens.

Recommended Strategies

- Improve the quality and accessibility of housing by increasing advocacy and community involvement.
- Develop a multidimensional strategy involving peer educators, social workers, and community health professionals.
- Address poor access to health care by providing
  - Transportation vouchers for physician visits
  - Funding for medications
  - Free clinics and volunteer health services
  - "Asthma-mobiles" that bring treatment into communities
  - Direct shipment of medications to patients.
- Provide educational materials that are appropriate to audiences' cultures, languages, and literacy levels.
- Form subgroups within coalitions to address special populations.
- Reduce allergens such as pollution and cockroaches.
- Develop reliable data and standard quality-of-life indicators.

Groups To Involve in Urban Asthma Control Efforts

- Public schools
- Head Start programs
- Child care providers
- Parents
- Public housing tenants
- Churches
- Community organizations
- Welfare-to-work programs
- Equal Employment Opportunity Commission programs
- Public health departments
- Hospitals
- Health maintenance organizations
- Community clinics and health centers
- Physicians and nurses
- Pharmacies
- Pharmaceutical companies

Making Coalitions Work: Keys to Success

Dr. Frances Butterfoss, a nationally recognized specialist in coalitions with the Center for Pediatric Research at Eastern Virginia Medical School in Norfolk, Virginia, shared her insights about the life cycles of successful and unsuccessful coalitions. She presented the results of a critical review of the literature on the effectiveness of consortia in changing health status and systems, which was performed by the Health Resources and Services Administration. The review found the following characteristics about successful and unsuccessful coalitions.

Successful coalitions

- Focus on a well-defined issue.
- Have an agreed-on vision and goals.
- Address unambiguous problems.
- Have solidarity among members.

Unsuccessful coalitions

- Have unrealistic or vague goals.
- Costs to members exceed their benefits.
- Are given responsibility without authority.
- Mandates are top-down and originate externally rather than internally.
- Timeframes for success tend to be unrealistic.

The expectations of coalitions were found to be a fundamental barometer of their performance.

In their first 2 years, coalitions should

- Establish a clear vision and mission.
- Formalize structure, processes, and procedures.
- Establish trust.
- Develop an unambiguous action plan.
- Identify group skills needed to manage coalitions.

In subsequent years, they should

- Monitor progress toward stated goals.
- Adapt to inevitable changes in leadership and membership.

Seven Steps to Coalition Success

Based on the research, Dr. Butterfoss outlined seven steps to coalition success:

1. **Clarify or reaffirm coalition vision and mission.** Because members often come and go, review the mission at least annually.
2. **Create community ownership of the coalition.** Involve the community in defining issues, identifying strategies, and developing tools and resources to implement and evaluate the strategies.
3. **Solidify the coalition structure and procedures.** Pay attention to processes, quality structures, and quantifiable outcomes. Form committees to complete specific tasks. Periodically ask what has been accomplished, what remains to be done, and what would be a reasonable plan for the future.
4. **Recruit and retain an active, diverse membership.** Continually ask who else should be in the coalition. Keep the coalition members happy and energized; if they are not kept satisfied, they will go elsewhere. Members expect that the benefits to them will outweigh the costs, that the issues the coalition addresses are worthwhile, and that they will have opportunities for leadership, networking, and self-empowerment.
5. **Develop coalition leadership, both formal and informal.** Develop election procedures and terms of office. Provide opportunities for training and technical assistance. Plan for transitions as members change and terms expire.
6. **Focus on action and advocacy.** Use strategic planning to identify long-term outcomes, but set realistic expectations. Evaluate the strategies used. To boost credibility and morale, use "quick wins," taking on tasks that are quickly achievable. Advocate to ensure that external institutions fulfill their responsibilities and to bring about policy changes that will benefit the community.
7. **Market the coalition.** Clarify its message and see that it is delivered. To attract attention, focus on data that document the problem and emphasize the coalition's accomplishments.

Surviving the Long Haul—Barriers and Strategies for Sustaining Coalitions

This breakout group, facilitated by Joy Grado, San Joaquin Valley Health Consortium, Fresno, California, addressed the question of how to sustain asthma coalitions over time in the face of numerous obstacles. The group identified common barriers to sustaining coalitions and suggested solutions, including ways the NAEPP can help.

Barriers

- Lack of structure.
- Lack of local data.
- Members' egos.
- Competition for funding and credit.
- Limited community awareness of asthma; indifference among payers.
- Tension between experts and laypersons and between families and professionals.
- Perception that coalitions are ineffective or confrontational.
- Limitations posed by structure. For example, if the coalition does not form a separate nonprofit organization, it can face logistical problems when it seeks funding.
- Bureaucratic institutions.
- Difficulty matching funders' needs with coalition's goals.
- Geography (long travel times impede meetings).
- Untrained coalition members.

Strategies

Funding

- Quantify direct and in-kind contributions of members and ask members to contribute uniform levels of support.
- Work with pharmaceutical companies. Allow them to promote education about the proper use of asthma medications (without promoting specific medications).
- Access local resources.
- Hire a grant writer.

Membership

- Recruit a diverse membership.
- Improve communication and information sharing, especially among committees.
- Address any previous barriers members may have encountered to ensure a fresh start and build trust.
- Support members equally.
- Put members' expectations and responsibilities in writing.
- Acknowledge members' successes.

Leadership

- Use personal contacts to recruit a diverse, qualified leadership.
- Ensure that leaders are sensitive to each member's needs and wants.
- Avoid titles.
- Establish a standing committee on leadership.
- Increase leaders' visibility across the community.

Processes

- Develop agreed-on timelines, goals, objectives, and outcomes.
- Celebrate the coalition's accomplishments.
- Establish some goals that are easily achievable ("quick wins") to build morale and credibility.
- Evaluate the coalition's structure, processes, programs, and strategies.

How NAEPP Can Help

- Locate funding sources.
- Facilitate networking.
- Organize additional coalition meetings.
- Synthesize and disseminate information from coalitions.
- Provide NAEPP materials for coalitions to disseminate.

Using the Media and Other Techniques To Communicate Messages

Most local asthma coalitions are grassroots organizations with limited resources for public relations. However, using the media and technology to carry their messages, they can extend their reach throughout their communities. This breakout group, facilitated by Dr. Sydney Parker, American College of Chest Physicians, and Ellen Sommer, National Heart, Lung, and Blood Institute, explored the possibilities, suggesting ways in which both coalitions and the NAEPP can maximize communication efforts.

Strategies To Promote Asthma Control Locally

- Request a mayoral proclamation to draw attention to asthma.
- Mobilize volunteers.
- Involve local celebrities as spokespersons.
- Print messages on grocery bags and fast-food tray liners.
- Write articles for local organizations' newsletters.
- Promote asthma education through churches, interfaith councils, and community festivals.
- Target alternative media to reach special audiences.
- Support national asthma awareness campaigns with community efforts.

How the NAEPP Can Support Local Initiatives

- Transform its Web site into a central point for coalitions to share information and resources, with a chat room, catalog of coalitions' materials, and links to coalitions' Web sites. (See article on pages 6–7.)
- Send press releases to national newspapers and medical societies, and alert coalitions so they can follow up with local contacts.
- Provide coalitions with press kits and tip sheets for working with the media.
- Develop templates for press releases, advertisements, and promotional materials, ready to be personalized by coalitions.
- Provide coalitions with bilingual education materials.

Partnerships With Local Schools—From Education to Clinical Intervention

Schools can help control childhood asthma, said Dr. Mark Millard, medical director of the Asthma and Pulmonary Rehabilitation Center at Baylor University Medical Center. To do so, school nurses and administrators need support and tools, especially peak flow meters. School-based efforts should involve families and address diverse communities. Most importantly, asthma medication must reach children who need it.

The Baylor Asthma Center offers proof of the potential success of school-based asthma initiatives. The Center, a community outreach component of the Baylor Health Care System, has been working with Dallas area schools since 1991 to help students with asthma succeed in school. The Center serves as a resource for school nurses and the school system's medical director; acts as a referral source for asthma care; and provides asthma education and materials for school nurses, students, and parents.

A Study of Access to Medication Versus Forced Compliance

Data show that the key to managing asthma is the appropriate use of anti-inflammatory medication, said Dr. Millard. However, treatment compliance is problematic. Administering medication at school may be one way of ensuring compliance.

In 1996, the Baylor Asthma Center, the Baylor University School of Nursing, and the Dallas Public Schools conducted a multischool study in Dallas County to test the effectiveness of access to medication versus forced compliance. The 4,000 Dallas students who have asthma are required to take medication in the nurse's office and to have a written plan signed by a physician. Students are not allowed to keep emergency bronchodilators with them at school.

The study involved 50 students with asthma of similar clinical severity. The students were randomly assigned to four groups: (1) no intervention, (2) home-based inhaled corticosteroids (ICS), (3) home-based ICS

plus education classes, and (4) school-based (forced) ICS. Eventually, the two home-based groups were consolidated and parents of this group received instructions on medication use. Peak flow rates and symptoms were monitored twice weekly at school for all participants.

At the end of the semester, the school-based (forced compliance) group had the highest rate of school attendance, the lowest rate of ED visits and hospitalizations, the lowest rate of doctor visits for exacerbation of asthma, and the lowest rate of rescue bronchodilator use. The home-based group also showed improvements across the board, but the outcomes were not as positive. The control group had the poorest school attendance rate and reported significantly more ED visits and hospitalizations than either intervention group.

Conclusions of the study were as follows:

- School-based medication administration can be a practical and effective way to control asthma through forced compliance.
- Providing medication for use at home in conjunction with monitoring at school can be effective in asthma management.
- The cost of drugs administered at school can be partially offset by improvements in school attendance.

Outreach to Local Schools

This breakout group, facilitated by Dr. Gail Brottman, Hennepin County Medical Center, Minneapolis, Minnesota, and Clare Wright, Norfolk Department of Public Health, discussed ways that coalitions can influence school-based asthma control initiatives.

Educate School Personnel and Parents

- Provide school nurses, health aides, and secretaries with copies of the NAEPP guidelines and materials.
- Provide in-service trainings to school nurses; offer continuing education units.
- Provide students with educational materials for their parents.

Add to School Curricula

- Advise teachers to use the ALA's "Open Airways" program in lesson plans. (See http://www.lungusa.org/asthma/astopen.html)
- Incorporate peak flow measurements into science and math curricula; offer educational programs to increase the general awareness of asthma among all students.

Advocate for Policy Change

- Emphasize that uncontrolled asthma can impair school performance, whereas proactive management can improve school performance by reducing absenteeism.
- Provide evidence of the link between asthma management and school performance.
- Work with the body that has oversight for school nurses (i.e., either the school system or the local health department).

Develop School Medical Policies

- Develop school policies to allow for the appropriate use of asthma medications by students and nurses.
- Identify students who need anti-inflammatory drugs. Institute standing orders for asthma medications to be administered by school nurses or health aides.
- Obtain signed medical information releases in advance to enable nurses to contact students' physicians if necessary.
- Ask ED physicians to alert the school nurse when a student has visited the ED because of asthma so that the nurse can check on the student the next day.

Potential Partners

- School nurses, health aides, and secretaries.
- Principals, superintendents, and boards of education.
- Physical education teachers and coaches.
- School bus drivers.
- School custodians (who control the use of potential irritants such as disinfectants).
- School system risk management staff.
- Special education coordinators.
- Nurses affiliated with local churches.
- Parents, especially those active in the PTA.
- Local ALA affiliates.
- Managed care organizations.
- Primary care providers.

Optimizing Patient Education—in the Office, Hospital, Pharmacy, and Other Settings

Good asthma management demands educated patients. Coalitions can help educate people with asthma and their families by working with health care providers and other influential groups throughout their communities. This breakout group, facilitated by Kim Farrior, Pitt County Memorial Hospital, Greenville, North Carolina, gave the following advice to facilitate patient education.

Education in the Provider's Office

- Recruit primary care physicians and their office staff to join asthma coalitions.
- Encourage physicians to have their staff perform important functions such as asking for patients' peak flow meter readings when they call the office.
- Give respiratory therapists the opportunity to provide education in doctors' offices. Use outcomes data to change physicians' behavior.
- Explore the possibility of creating an asthma educator certification to increase the quality of education, and seek reimbursement by payers for asthma education.

Messages and Materials

- Create quick-reference materials on asthma symptoms and treatment for health care professionals, such as laminated pocket cards.
- Standardize asthma messages using the NAEPP guidelines.
- Consider using technologies such as the World Wide Web, local access cable stations, teleconferencing, and telemedicine to provide education.

Reach Out to Others

- Involve pharmacies as a point of information dissemination.
- Include church-affiliated nurses in outreach strategies.
- Encourage EDs to provide patient education and referrals to their patients. Educate ED staff and involve them in coalitions. Demonstrate the cost savings of reduced ED visits.
- Reach out to youth groups and sports teams.
- Target child care providers.

Outreach to the Health Care Sector

Health care professionals, managed care organizations, and insurers are important partners for asthma coalitions, but coalitions may encounter barriers to working effectively with them. To improve outreach to providers and payers, this breakout group, facilitated by Dr. Ileen Gilbert, Case Western Reserve University Medical School, suggested the following strategies:

- Meet local needs by recruiting physicians who will champion the coalition's work. Incorporate positive, hands-on programs.
- Ensure that materials for use in physicians' offices are user-friendly and include action plans and clear instructions. Develop standardized education programs based on the NAEPP guidelines.
- Work with health plans to identify and educate physicians whose patients have too many hospital admissions for asthma. Send asthma management information to patients identified as having asthma, and send a copy to their physicians.
- Seek improvements in residency training.

Target Groups

- Emergency medical services staff
- Physician office staff
- Trainees at academic medical centers
- Home health agencies
- Social services providers
- School nurses and secretaries/health aides
- Pharmaceutical companies
- Durable medical equipment companies

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